NATIONAL HEALTH SERVICE CORPS EDUCATIONAL PROGRAM FOR CLINICAL AND COMMUNITY ISSUES IN PRIMARY CARE

ETHICS MODULE

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GENERAL INTRODUCTION

The purpose of this module is to assist teachers and learners in having an orderly and lively discussion of some ethical problems that arise in primary care settings. The authors believe that most apparent ethical disagreements in clinical settings are really disagreements about facts, or communications problems, and that consensus is often possible after extended discussion. Good ethics starts with good facts. The cases included here are designed to help discover areas of disagreement, as well as to expose issues about which reasonable people do disagree. The discussions, therefore, should result in some narrowing of apparent disagreement: people who do the work should experience some narrowing of their apparent differences. But it will also leave some people uneasy because true disagreements will probably remain. We believe that many of these can be narrowed with further discussion, but probably not within the hour.

The other benefit of the module is that it should evoke in each person a better understanding of the cases and issues. Everyone should be able to say at the end of each session that they have a more informed and nuanced view than they had before. At first, this can be unsettling. In the words of Ecclesiastes,

> *In much wisdom is much grief,*
> *And whosoever increaseth understanding increaseth sorrow.*

In the long run, there should be satisfaction in realizing that one's ethical views are better informed and better thought out. It is not always easy to discern the right answer to an ethical problem, but it is often easy to identify a wrong answer: one that is based on bad facts, failure to consider alternatives, or inconsistent reasoning.

In addition to the recommended readings at the end of each subtopic, the following general references are practical and authoritative, for the student who would like to pursue medical ethics in greater depth.

GENERAL REFERENCES

Beauchamp TL, Walters L, eds. *Contemporary Issues in Bioethics*. Fifth edition. Wadsworth Publishing: Belmont, CA, 1999.
One of the most widely used anthologies of articles about bioethics. It contains an excellent introduction to ethical theory as it applies to medicine and health care.

Christie RJ, Hoffmaster CB. *Ethical Issues in Family Medicine*. Oxford University Press: New York, 1986.
A family practitioner and a philosopher teamed up to write this excellent discussion of ethical issues that arise in a primary care family medicine practice. The writing is conceptually sound and practical at the same time.

Singer PA, et al. Bioethics for Clinicians. *Canadian Medical Association Journal* 1996;155:189–190.
This is an excellent 14–part series covering basic concepts in bioethics, published in 14 consecutive issues of the Journal. It is also available on the Web at www.utoronto.ca/jcb. There are excellent bibliographies at the end of each article.

Reich WT, ed. *Encyclopedia of Bioethics*. Second edition. Macmillan: New York, 1995 (5 volumes).
An expensive but comprehensive collection of articles and bibliographies, written by many of the leading scholars in the field.

BIOETHICSLINE.
An electronic and hard-copy database maintained by the National Library of Medicine with the assistance of the Kennedy Institute of Ethics at Georgetown University. BIOETHICSLINE can now be searched for free on the Web, by going to http://bioethics.georgetown.edu, and clicking on the appropriate link. If you prefer, you can call their staff at 800-MED-ETHX (800-633-3849).

SUBTOPIC 1

CONFIDENTIALITY

TIMELINE (60 minutes)

5 min	Introduction/Ice Breaker
5 min	Review of Objectives
10 min	Overview
35 min	Review of Case/Questions
5 min	Additional Questions and Answers

SECTION 1 LEARNING OBJECTIVES

Target Group: Physicians in training and in practice, nurse practitioners/trainees, physician assistants/trainees, and other health professionals/trainees.

By the end of this discussion, participants should be able to:

1. State two purposes of the principles of confidentiality.

2. State three general reasons that are used to argue for breaching confidentiality in certain instances.

3. Give specific examples of situations in which confidentiality can be breached based on each of the reasons.

4. Understand how disclosure of HIV status has traditionally been treated in this country.

5. Understand how disclosure of HIV status is more commonly being treated now.

SECTION 2 ICE BREAKER

Ask the participants to write down (1) the number of diseases they think have to be reported to the public health department in their state, and (2) the names of as many of those diseases as they can. After they are done, see what numbers they came up with, and how widely they might differ. Also, compare what diseases are on the lists of most of the participants. (You might have to modify this somewhat if the participants are not all from the same state.)

It would be helpful for you to know ahead of time what diseases are reportable in the state you are in. Probably most people are going to be surprised at the number of diseases that are reportable. In Kansas, for example, there are 40 reportable diseases. The full list (not including HIV, which is treated under separate rules) is: amebiasis, anthrax, botulism, brucellosis, campylobacter infections, chancroid, chickenpox, chlamydia (including psittacosis), cholera, diphtheria, encephalitis, giardiasis, gonorrhea, granuloma inguinale, viral hepatitis, legionellosis, leprosy, Lyme disease, lymphogranuloma venereum, malaria, measles (rubeola), meningitis, mumps, pertussis, plague, poliomyelitis, rabies, rheumatic fever, Rocky Mountain spotted fever, rubella, salmonellosis, shigellosis, syphilis, tetanus, toxic-shock syndrome, trichinosis, tuberculosis, tularemia, and yellow fever. You might mention a few of these to the participants, and see how many of them they are surprised to learn are reportable.

SECTION 3 OVERVIEW

The word *confidentiality*, derived from the root *fidele*, meaning trust, is one of the oldest and most basic principles in medical ethics. It refers to the importance of the patient being able to trust the doctor (or other provider) not to reveal personal and private information without the patient's permission. The principle of confidentiality is intended to limit breaches of the patient's privacy to those who have a need to know in order to treat the patient.

By protecting patients' rights through the principle of confidentiality, two very distinct goals are advanced. In the first place, by assuring patients of confidentiality, we can facilitate effective evaluation of the individual patient. Accurate diagnosis depends on a complete history. The patient is less likely to reveal personal and potentially embarrassing information if he or she cannot trust the provider to maintain confidentiality. When disclosure can be damaging, as in the case of AIDS or mental illness, the patient may be inhibited from even seeking medical care if she does not have a high degree of trust in the doctor.

A second goal relates to the health of the community as a whole. Society benefits, for example, if patients with contagious diseases or mental illness seek and obtain early treatment. If treatment (or appropriate counseling about behavior) is effective, the community benefits by a lower rate of new cases, or by restoring the functioning of sick people and preserving their productivity.

Confidentiality is appropriately waived when the patient consents to it. Sometimes this consent is not entirely a matter of free choice, as when a patient must consent to release of information to an insurance company if he or she wants the medical care to be paid for. Similarly, a patient may agree to disclosure of private information to students in a teaching setting, even though the student may not have a need to know from the patient's perspective. Whether or not this kind of disclosure is voluntary depends in part on whether the patient has a choice about where to seek care.

The health care provider's duty to keep information about a patient confidential is not absolute, however. Providers have duties not just to their patients, but also to society in general. Sometimes, those latter duties can be important enough to override the duties to the patient. There are three broad categories in which duties to others might justify a breach of confidentiality: (1) a threat to the patient; (2) a threat to other unidentified persons, and (3) a threat to some other specific individual.

A health care provider's decision to disclose information without the patient's consent, or over his objection, should not be made lightly. The clearest justification is when there is a legal duty to disclose, such as a statute requiring reporting of specified contagious diseases. Similarly, child abuse reporting statutes require all health care providers to disclose sensitive and potentially damaging information obtained from parents. Such statutes effectively embody society's determination that, based on one or more of the general principles stated above, the benefits from the breach of confidentiality outweigh the "wrong" to the patient.

SECTION 4 CASE STUDY/DISCUSSION QUESTIONS

Edgar, a 16–year–old male, has asked for a confidential appointment with you in the teen-age clinic. He states that he is sexually active in a monogamous relationship and requests an HIV test. The test is positive and, despite extensive counseling, he insists that he does not plan to inform his girlfriend, Diana. He also demands that you not interfere.

1. Assuming that your state law permits it, should you inform Diana?

2. Would it make a difference if Edgar said (believably) that he loves Diana, and has kept a promise that he will always use a condom?

3. How might you behave if there is a state law that forbids disclosure?

4. If you feel that there is a duty to disclose, should you warn Edgar about this possibility before you perform the HIV test?

SECTION 5 SUGGESTED ANSWERS

1. *Assuming that your state law permits it, should you inform Diana?*

To understand the issues relating to the disclosure of a patient's HIV status, a historical detour is necessary. Traditionally, in the case of sexually transmitted diseases, disclosure to sexual partners of the patient has been mandated. Depending on a state's law, this would often take place by having the provider report the illness to a state public health agency, which would in turn follow up by notifying the partners.

In the case of HIV, however, the initial response by state governments was different. Numerous laws were passed that guaranteed confidentiality to patients. Indeed, in many cases it was similarly determined that there would even be no reporting of the patient's identity to any public health agency. The reasons for this response related in large part to the stigmatization that would likely result if a person's HIV-positive status became known. The harm to the patient from a breach of confidentiality was considered so great as to outweigh the possible benefits to others from disclosing that status. Thus, in Ronald Bayer's phrase, "HIV exceptionalism" best describes how disclosure of HIV status was treated in a manner that differed from our usual response to sexually transmitted diseases.

Over time, however, with changes in our ability to treat the disease, and changes in public attitudes, that response has been modified. There is a growing recognition that a balance should now be struck that places greater weight on the needs of society, with a resulting weakening of the rights of individual patients. More and more, disclosure issues relating to AIDS are being treated like those relating to other similar diseases. Indeed, even members of the AIDS community are in some instances supporting requirements that there be named reporting to public health authorities of persons who are HIV-positive.

How does this background help us answer the question? First, any health care provider should know their state's laws relating to HIV reporting, and what the health authorities do with information that is reported to them. (A particular state may even have different rules relating to those persons who are merely HIV-positive, as opposed to persons who have AIDS.) Consistent with the changed attitudes, your state law might require named reporting, with follow-up notification of sexual contacts. Alternatively, it might allow the health care provider, at his or her discretion, to notify sexual contacts.

Assuming that state law allows such disclosure, it would certainly be ethical for a provider to disclose the patient's HIV status to the patient's partners (or, if the patient is willing, allow the patient to make such disclosure himself). The risk to the health of the partner is sufficient to override the patient's right to confidentiality. A person's HIV status should not be viewed as giving them any special right to expose others--*unknowingly*—to this disease. As the American Medical Association has stated:

"Exceptions to confidentiality are appropriate when necessary to protect the public health or when necessary to protect individuals, including health care workers, who are endangered by persons infected with HIV. If a physician knows that a seropositive individual is endangering a third party, the physician should, within the constraints of the law, (1) attempt to persuade the infected patient to cease endangering the third party; (2) if persuasion fails, notify authorities; and (3) if the authorities take no action, notify the endangered third party." Council on Ethical and Judicial Affairs, American Medical Association, Code of Medical Ethics, 1996-97 Edition, Opinion 2.23.

2. *Would it make a difference if Edgar said (believably) that he loves Diana, and has kept a promise that he will always use a condom?*

   Ultimately, we must return to the question of whether it is ethical for anyone to expose someone else to a possibly fatal illness without that person's consent. The person being exposed is Diana, not the health care provider, and it is she who is entitled to make the decision of whether she wants to sleep with Edgar, assuming that he uses a condom. Even in that instance, having sex with Edgar will not be risk free. Moreover, assuming that Edgar fails to keep his promise, the person who suffers will be Diana.

3. *How might you behave if there is a state law that forbids disclosure?*

   Such a law would obviously make things very difficult for a provider who believes that it is inappropriate for a partner to be unknowingly exposed to AIDS. One recourse for such a provider would be to make sure that they are not in a position to have to deal with this dilemma, by talking to their employer and seeing if their job can be tailored appropriately. This would be similar to other situations in which a person's own moral beliefs are respected, such as a nurse who opposes abortion not being required to surgically assist in abortion procedures.

   Alternatively, the provider might inform any patient who is getting tested for HIV about the provider's belief in the appropriateness of partner notification, and see if the partner consents to allowing notification. If they do consent, then there is no problem. If they do not consent, the provider should attempt to find a colleague who is willing to take care of the patient and uphold the legal standards of no disclosure to partners.

4. *If you feel that there is a duty to disclose, should you warn Edgar about this possibility before you perform the HIV test?*

   Failure to warn Edgar before he consented to the test might appear to violate his right to make an informed choice about getting tested. It might be viewed as breaking an implied promise, since Edgar might have assumed that the information would be kept confidential.

On the other hand, as a legal matter, people are assumed to be familiar with the law, and so if the law mandates disclosure, Edgar would have been making an incorrect assumption. Thus, you could argue there is no breach of a promise. For example, if a patient is about to reveal the name of someone else that they intend to kill, most providers would probably not feel the need to suddenly interrupt the patient and remind him that you might reveal this information to the police.

The American Medical Association, in the policy statement that was discussed above, does indicate that the limits on the confidentiality of test results should be discussed with a patient before performing an HIV test. In addition, state law may also specifically require such a discussion, and the health care provider should be very familiar with the details of any such laws.

SECTION 6 SUGGESTED READING

1. Bayer R. Public health policy and the AIDS epidemic: An end to HIV exceptionalism. *New England Journal of Medicine* 1991;324:1500–1504.
   An excellent review of the history of how the public health community dealt with the confidentiality issues related to AIDS, together with rather foresighted observations about how that treatment was changing even as of 1991.

2. Bayer R, Toomey KE. HIV prevention and the two faces of partner notification. *American Journal of Public Health* 1992;82:1158–1164.
   An analysis of the two traditional concepts in control of sexually transmitted disease—duty to warn and contact tracing—and the ethical and political tradeoffs in each.

3. Council on Ethical and Judicial Affairs, American Medical Association. *Code of Medical Ethics: Current Opinions with Annotations*. American Medical Association, 1996-97 edition, Chicago, IL.
   The source for the opinion quoted in the discussion, this volume gives the views of one prominent health care organization on a wide variety of matters. In addition, it has extensive references to articles and court decisions that cite these opinions.

4. Fleck L, Angell M. Please Don't Tell! *Hastings Center Report* 1991;21(6):39–40.
   Case study involving issue of whether to reveal patient's HIV-positive status to one of her care-givers.

5. Gostin LO, Curran WJ. AIDS screening, confidentiality and the duty to warn. *American Journal of Public Health* 1987;77:361–365.
   An argument for strict standards of confidentiality, based on the low efficacy of treatment at the time this was written.

6. Gostin LO, Ward JW, Baker AC. National HIV case reporting for the United States: A defining moment in the history of the epidemic. *New England Journal of Medicine* 1997;337:1162–1167.
   A call for a uniform national reporting of AIDS cases, coauthored by a prominent academician, a government official, and a representative of the AIDS advocacy community.

7. Kleinman I, Baylis F, Rodgers S, Singer P. Bioethics for clinicians: Confidentiality. *Canadian Medical Association Journal* 1997;156:521–524.
   An excellent brief review of the basic ethical and legal principles (under Canadian law, however) relating to confidentiality. This can also be found on the Web, at www.cma.ca/cmaj/vol-156/issue-4/0521.htm.

8. Ubel PA, Zell MM, Miller DJ, Fischer GS, Peters-Stefani D, Arnold RM. Elevator talk: Observational study of inappropriate comments in a public space. *American Journal of Medicine* 1995;99:190–194.

The authors eavesdropped in hospital elevators, and then evaluated the appropriateness of the various types of comments that they heard.

SECTION 7 RESOURCES

1. MedEthEx. MCP Hahnemann University. griffin.auhs.edu/dept/medethic
   Multi-media series of four ethics cases on the web. Case 1 involves an HIV-positive woman who does not want her husband told about her illness. There is an extensive accompanying bibliography.

2. Ethics in Medicine. University of Washington School of Medicine. eduserv.hscer.washington.edu/bioethics/topics/aids.html
   Four brief cases involving ethical issues related to AIDS, with an accompanying discussion and bibliography.

3. Ethics in Medicine. University of Washington School of Medicine. eduserv.hscer.washington.edu/bioethics/topics/confiden.html
   A brief case involving confidentiality, with an accompanying discussion and bibliography.

SUBTOPIC 2

INFORMED CONSENT

TIMELINE (60 minutes)

5 min	Introduction/Ice Breaker
5 min	Review of Objectives
10 min	Overview
35 min	Review of Case/Questions
5 min	Additional Questions and Answers

SECTION 1 LEARNING OBJECTIVES

Target Group: Physicians in training and in practice, nurse practitioners/trainees, physician assistants/trainees, and other health professionals/trainees.

By the end of this discussion, participants should be able to:

1. Understand how the concept of patient autonomy has changed the relationship between patients and health care providers during the past half century.

2. Describe how the concept of informed consent supports patient autonomy.

3. Describe the basic categories of information that must be discussed as part of informed consent.

4. List the circumstances in which informed consent need not be obtained.

5. Discuss the role of a patient's cultural beliefs in determining ethical behavior toward that patient.

6. Discuss the appropriate way in which the amount of information given in the consent process can be tailored to each patient.

SECTION 2 ICE BREAKER

Ask the participants if they know the current recommendations from the American Academy of Pediatrics with regard to male circumcision. In case no one does, note that as of March 1999 (and published in the issue of *Pediatrics* for that month), the AAP concluded that the health benefits of this practice do not justify routine circumcision. This position has changed several times: back in the 1970's, it had said there was no medical indication for male circumcision, but in 1989, it had concluded there were potential medical benefits.

Given the current position, ask the participants to discuss if it is still OK for parents to request circumcision for their own child. And if they think it is OK, why is it OK (given that the procedure is not risk-free, and may lead to disabling penile injuries in a small percentage of cases)? More generally, if we are allowing this risk to children in order to meet the "cultural" or "religious" need of parents, how do we determine when we should allow these cultural needs to triumph? In Africa, a more disfiguring practice often known as female circumcision takes places. See if participants wish to condemn the African practice and yet defend the male circumcision that takes place in the United States. (Note the difficulty of ever getting the true party in interest—the child—to consent to these practices!)

SECTION 3 OVERVIEW

The relationship between health care providers and their patients has changed dramatically in the past half century. One of the single greatest changes has been an increased recognition of the need to respect patient *autonomy*. Previously, *paternalism* would have often been an appropriate description for how providers (and, in particular, doctors) behaved. The provider would have acted like a parent, deciding what was best for the patient, and then merely telling the patient about that conclusion, with the expectation that the patient would then comply with the proposed treatment. With the shift to emphasis on patient autonomy, there is a recognition that the patient's desires and values should play a far more significant role in determining what treatment decisions are made. It is, after all, the patient's life (or health) that is at stake.

Doctrine of Informed Consent

It is through the developing doctrine of informed consent that the new attention to patient autonomy has had its greatest impact. Autonomy would be a useless concept if the patient were not given the information needed to make a meaningful choice about medical care. Accordingly, as part of the process of informed consent, a competent patient should be given information about the proposed treatment or procedure, including both its **benefits** and **risks**, in addition to information about any **alternatives** to the proposed treatment (including the benefits and risks of the alternatives). One alternative that should almost always be discussed is what would happen if the patient were to do nothing—in other words, what is their prognosis? (See Handout/Overhead 1 for a list of the basic elements of the informed consent process.)

An important thing to remember is that informed consent is a process, and not a form. The signing of a consent form is merely to document that an appropriate discussion took place with the patient. It is that discussion that constitutes the process of informed consent. Thus, you should remember that informed consent is relevant for any decision that a patient has to make, and not merely for "procedures" in which there is a pre-printed consent form.

Exceptions to Informed Consent

When is informed consent not needed? Sometimes it is not possible to get informed consent, since the patient is temporarily incapable of consenting. For example, a patient may be wheeled into an emergency room, unconscious, after an automobile accident. They need immediate attention. In such a circumstance, it is assumed that the patient would have consented were they able to ("implied consent"), since most of us would want to be given treatment in those circumstances.

When a patient is incompetent and it is not an emergency, then an effort should be made to get the consent of a surrogate decision-maker. This is usually a family member, or someone who has been appointed by the patient to make such decisions under an advance directive. Be aware, however, that just because a patient may be incompetent for making some decisions—such as controlling their finances—it does not mean that they are

incompetent for purposes of all health care decisions. If the patient can demonstrate an understanding of the issues that confront them, and an ability to reason about those issues, then they should be involved in the consent process. Indeed, this is what is typically done with children: in addition to having their parents agree to a treatment, it is appropriate that a child who is old enough also be given the opportunity to agree.

Scope of Informed Consent

How do you determine the amount of information that should be given to the patient? In terms of state laws, there are two general rules that are adopted, and you should find out which rule applies in your state. Some states use what is called the "professional standard": the amount of information that must be disclosed is determined by what your fellow professionals are actually doing in talking to their patients. Thus, if a lawsuit is brought claiming lack of informed consent, other providers will have to testify as to whether you did or did not present the information that is usually presented in such circumstances.

The other type of rule is called the "reasonable person" standard: the provider is required to present the information that a reasonable person would want to know if he or she were in the same situation as the patient. Under this rule, it is irrelevant what other providers are doing. Even if none of your colleagues are mentioning a particular risk, you might have failed to get adequate informed consent if an average person would want to know about that risk. The "reasonable person" rule is the newer rule, and is more consistent with the attention being given to patient autonomy. It is also more consistent with general concepts of medical ethics. Accordingly, no matter what the law is in your state, it makes sense to determine the scope of your informed consent discussions based on what a reasonable person would want to know.

There is a long-standing doctrine called "therapeutic privilege" under which a provider might withhold relevant information from the patient on the ground that knowing it might harm the patient. For example, a patient might have severe heart disease that makes him or her likely to have a heart attack if he or she is subjected to stress. A provider might conclude that under this circumstance, it is best not to tell the patient the full truth about the seriousness of their condition. *This doctrine should be invoked very rarely, if at all*: otherwise, there is a danger that the provider will end up making important decisions for the patient. In effect, we would be reverting to the paternalism that used to characterize provider-patient relationships.

Finally, it should be noted that there is no obligation to tell the patient information that they do not want to know. Letting the patient decide how much information they want is fully consistent with respecting the patient's autonomy. This concept is further explored in the case that follows, particularly with regard to possible conflicts between a patient's cultural background and the view of patient autonomy that has been described herein.

SECTION 4 CASE STUDY/DISCUSSION QUESTIONS

While working in the general medicine clinic, you are taken aside by the wife of Mario M., a 70–year–old patient who you are scheduled to see later in the morning. She indicates that she has recently dealt with the illness and death of her sister from cancer, and that she is worried—based on his symptoms, such as weight loss—that Mario also might have cancer. She asks that you not specifically mention cancer in talking with her husband, since she knows that he would deal poorly with such news. She asks that you instead talk with her first.

Later in the morning, after examining Mario, you do indeed begin to suspect that he might have some form of gastro-intestinal malignancy. In terms of discussing the additional work-up, you would normally raise the possibility of cancer with a patient at this stage.

1. Should you defer mention of cancer, and instead merely tell the patient that there are a range of possibilities you are looking into?

2. Would your answer change if Mario's wife had (truthfully) also told you that she and her husband had only recently moved to the United States from Italy to live with their adult children, and that in Italy it was a common practice not to tell patients about the existence of life-threatening illnesses?

3. Assuming that Mario had been a long-standing patient of yours, what might you have previously done that could have simplified the resolution of the issues raised in the two prior questions?

SECTION 5 SUGGESTED ANSWERS

1. *Should you defer mention of cancer, and instead merely tell the patient that there are a range of possibilities you are looking into?*

   This question presents a difficult dilemma: you want to do what is best for the patient, and you have some information, from his wife, that he should not be told about the possible poor prognosis. Under what theories might you decide to follow the wife's advice? First, you might conclude that she knows her husband well, and that learning about his cancer might indeed harm his health. As noted, this would probably constitute an application of the doctrine of "therapeutic privilege." And, as discussed in the Overview, providers should hesitate to apply that doctrine. It is all too easy for providers to think that they know best in terms of deciding how much a patient should know.

   Does the information from the patient's wife make it somewhat easier to apply therapeutic privilege? Probably so, yet the provider should nonetheless hesitate in altering the amount of information disclosed to the patient. As noted, it is the concept of patient autonomy that led to the development of informed consent. Just as it was inappropriate to have providers making decisions for patients, it is similarly inappropriate for relatives to be making decisions for patients. In both cases, it is the patient whose life is at stake, and it is they who have the right to have adequate information about the choices that confront them. (Indeed, you might note that even discussing the details of a patient's health problem with a relative—whether a spouse or an adult child—can be a breach of confidentiality, assuming the patient did not consent to that discussion.)

   An alternative theory for following the wife's advice is that she is not predicting whether or not knowing about the diagnosis will harm Mario, but rather is merely saying that she thinks he would not want to know about the possible cancer. Again, however, there is a great danger in accepting somebody else's word about what a patient would or would not want to know. This issue is discussed further in the answer to the next question.

2. *Would your answer change if Mario's wife had (truthfully) also told you that she and her husband had only recently moved to the United States from Italy to live with their adult children, and that in Italy it was a common practice not to tell patients about the existence of life-threatening illnesses?*

   This question is again raising the issue suggested in the last question: Mario's wife is suggesting that we would perhaps be advancing Mario's autonomy by not telling him about the possible cancer because he would not want to know this. (Note how this is quite different than the doctrine of therapeutic privilege: under this argument, we are advancing his autonomy, as opposed to overriding it.) While in the previous question all we had to support the wife's viewpoint was her own opinion of what her husband wanted, now we have an additional element: the

fact that Mario's culture often supported not fully disclosing information to patients.

This question raises a difficult dilemma: To what extent should patients in this country be treated consistent with the ethical rules of their own culture, if those ethical rules differ from the dominant ethical rules in the United States? While the question presents this dilemma in the context of an Italian patient, this issue is most commonly discussed in the context of the Japanese, whose culture has retained strong elements of paternalism. In particular, in the context of a diagnosis of an incurable cancer, many Japanese physicians would view their telling the patient the truth as being cruel to the patient by denying them the last shred of hope. In essence, the claim is that the Japanese people have determined that it is best for the provider not to reveal this terminal diagnosis. Instead, what takes place is a type of stylized "play" acted out between patient and provider. The provider might note there is an abnormal mass, and observes that it is not cancer, but that to be on the safe side, it should be treated as if it were cancer.

The conflict between differing ethical rules in different cultures is often discussed in the context of "ethical relativism": absent any proof that a particular culture's ethical rules are somehow superior, how does one choose which rules to apply? In the context of Mario, the best choice is to apply the predominant rules in this nation. For even in Italy (and Japan), there are gradual changes taking place, with more and more patients objecting to the notion that patients should be partially left out of the decision-making process. And, if you do not tell Mario about the diagnosis, you have no way of knowing what he really wanted. It is quite possible that he is one of those Italians who view the increased attention to patient autonomy as a good thing. By not telling him about the possible cancer, you might be depriving him of those very rights that he would want.

3. *Assuming that Mario had been a long-standing patient of yours, what might you have previously done that could have simplified the resolution of the issues raised in the two prior questions?*

The dilemma in this case study is that we did not really know what Mario wanted. We were forced to guess that he might not want to know about the cancer. That guess could be supported by different pieces of information—what his wife says about his opinions, or the fact that he comes from a culture in which people do not want to be told certain kinds of bad medical news. Nonetheless, we are still left guessing, and that is not the best of reasons for depriving a patient of information that they are entitled to know.

On the other hand, Mario does have a right to refuse certain kinds of information. Thus, if Mario is a long-term patient of ours, the best solution is to find out, ahead of time, whether in fact he does want to have certain information kept from him. This is a useful discussion to have with any of your patients—after all, some of us really don't want to hear about a fatal diagnosis—and it is especially useful if you are dealing with patients whose cultural background suggests that they might

expect not to be told of, for example, a terminal cancer. Providers who deal with such patients might, while they are still healthy, ask them who much they would want to know in such circumstances. The provider might even get authorization for telling the "withheld" information to a spouse or adult child. All of these conversations should be appropriately documented in the patient's chart. In some cases, the patient might even fill out a type of advance directive that addresses these issues.

Of course, even when this has not been done ahead of time, there is still an opportunity to discuss with the patient how much they want to know. Even if you tell Mario about the possibility of cancer, you can still ask him if he wants you to avoid telling him later if there is truly "no hope." He has a similar right to ask not to be told the specific survival statistics (e.g., 6 months, 1 year, 5 years) that might relate to his condition. In all of these situations, however, the key point is that the decision not to know is being made by Mario—not by a relative, not because of his culture, and not by the health care provider.

SECTION 6 SUGGESTED READING

1. Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. *Journal of the American Medical Association* 1995;274:820–825.
   A study examining attitudes of various ethnic groups in the United States towards end-of-life care and truth telling. This journal issue also contains another article on this topic (about Navajo culture) and an editorial, at pages 826 and 844, respectively.

2. Lantos J. What should Leah be told? *Second Opinion* 1993;18(4):81–86.
   A narrative about a real case, involving an 18–year–old Israeli girl with cancer who was being treated in an American hospital, and who was telling the health care team that (consistent with her culture) she wanted her father to make all the decisions, and that she didn't want to even know what surgery was about to be done to her.

3. Leflar R. Informed consent and patients' rights in Japan. *Houston Law Review* 1996;33:1–112.
   Since this is written for a legal audience, it is somewhat technical. Nonetheless, it is a fascinating discussion about what actually happens between doctors and patients in Japan, and how change is gradually taking place.

4. Meisel A, Kuczewski M. Legal and ethical myths about informed consent. *Archives of Internal Medicine* 1996;156:2521–2526.
   A brief but excellent review of common misconceptions among health care providers about the doctrine of informed consent.

5. Pellegrino ED. Is truth telling to the patient a cultural artifact? *Journal of the American Medical Association* 1992;268:1734–1735.
   A response by a prominent American bioethicist to the issues raised in the essay by Surbonne (cited below) about cultural conflicts.

6. Surbonne A. Truth telling to the patient. *Journal of the American Medical Association* 1992;268:1661–1662.
   An Italian oncologist discusses her personal responses to having dealt with truth-telling issues while working in the United States and in Italy.

SECTION 7 RESOURCES

1. MedEthEx. MCP Hahnemann University. griffin.auhs.edu/dept/medethic
   Multi-media series of four ethics cases on the web. Case 4 involves whether to tell a Japanese man about his cancer diagnosis. An extensive bibliography is provided.

2. Ethics in Medicine. University of Washington School of Medicine. eduserv.hscer.washington.edu/bioethics/topics/cross.html
   Three brief cases involving cross-cultural conflicts in the pediatric setting, with a bibliography.

3. Ethics in Medicine. University of Washington School of Medicine. eduserv.hscer.washington.edu/bioethics/topics/consent.html
   Two cases involving informed consent issues, with accompanying discussion and a bibliography.

4. Consent and Capacity. University of Toronto Joint Centre for Bioethics. www.utoronto.ca/jcb/consent_&_capacity.htm
   Extensive collection of links relating to informed consent. Included are links to (1) the Royal College of Physicians and Surgeons of Canada Bioethics Education Project, which has on-line cases involving informed consent for a number of different medical disciplines (medicine, obstetrics and gynecology, psychiatry and surgery), and (2) the 14-part series of articles entitled "Bioethics for Clinicians", which was published in the Canadian Medical Association Journal, and is available on-line (including Part 1, Consent, and Part 7, Truth Telling).

5. Department of Bioethics. Cleveland Clinic Foundation. www.ccf.org/ed/bioethic/biocon11.htm
   A brief discussion of a case involving telling a patient who is not a U.S. native about a diagnosis of AIDS.

6. The Ethical Question. American Medical Association, 1993.
   One of the four videotapes (with accompanying study guides) in this package is entitled "Informed Consent," and covers the various elements involved in the concept, in addition to issues relating to getting informed consent when the patient lacks decision-making capacity.

   Contact: Write to the AMA at Division of Continuing Medical Education, American Medical Association, 515 North State Street, Chicago, IL 60610, or call (800) 621-8335.

7. Fanlight Productions. www.fanlight.com
   Among the large collection of videotapes sold by this company is "Deception", which deals with whether or not an elderly patient's latent syphilis should be treated without telling her about it.

Contact: In addition to using the web site address given above, you can write to Fanlight Productions, 47 Halifax Street, Boston, MA 02130, or call (800) 937-4113.

SECTION 8 HANDOUTS/OVERHEADS

(Attached)

Basic Elements of Informed Consent

A. Diagnosis

B. Nature of the Proposed Treatment
(What does the treatment involve?)

C. Purpose of the Proposed Treatment

D. Risks or Side Effects of the Proposed Treatment

E. Probability that the Proposed Treatment will Succeed

F. Alternatives to the Proposed Treatment

1. For each alternative, discuss its risks and benefits.
2. The consequences of "no treatment" should always be discussed.

G. "Exceptions" to Informed Consent

1. Emergencies—If there is no time to get a person's consent, but it is likely that they would have consented.
2. Therapeutic Privilege—A provider's determination that knowing the complete truth might harm the patient. This should rarely be used.
3. Incompetent Patients—Since the patient cannot consent, one must find out who is authorized to consent on behalf of the patient.

Informed Consent is a *process* involving discussion between a provider and a patient: it is *not* the "signing of a consent form."

SUBTOPIC 3

WITHDRAWING CARE

TIMELINE (60 minutes)

5 min	Introduction/Ice Breaker
5 min	Review of Objectives
10 min	Overview
35 min	Review of Case/Questions
5 min	Additional Questions and Answers

SECTION 1 LEARNING OBJECTIVES

Target Group: Physicians in training and in practice, nurse practitioners/trainees, physician assistants/trainees, and other health professionals/trainees.

By the end of this discussion, participants should be able to:

1. Describe the rights that patients have with regard to the withdrawal of care.
2. Describe the rules relating to the withdrawal of artificial hydration and nutrition.
3. Discuss the differences and similarities between withholding and withdrawing care.
4. Understand the differences between withdrawing care, suicide, and assisting in suicide.

SECTION 2 ICE BREAKER

Ask the participants if they can remember anything specific about Dr. Jack Kevorkian's patients. What kind of medical problems did they have? Why were they seeking his help? The discussion should perhaps bring out some of the differences between being free from pain and being free from suffering (or perhaps also Kevorkian's poor choice of patients). (Among his patients were persons with amyotrophic lateral sclerosis, Alzheimer's disease, multiple sclerosis, pelvic pain with no known organic etiology, cancer, and chronic fatigue syndrome).

As a follow-up, ask them if they can describe—again, in some detail—what it was that Dr. Kevorkian did for the patients. The discussion should highlight the fact that the patients needed him to create a device by which they could do something simple—e.g., pressing a button—that would lead to their deaths. Their "need" for these devices will be something that will distinguish them from the patient that will be discussed in the case. (In addition, you might point out that the one time he was finally convicted—for second degree murder, in March 1999, based on the case that was shown on national television on *60 Minutes*—it involved a situation in which the patient did *not* press a button, etc., but rather Kevorkian himself injected the drug that killed the patient.)

SECTION 3 OVERVIEW

Every person will eventually die. Most will die under a doctor's supervision, and most die in a hospital. In the usual case, death is anticipated, and it can often be prolonged or postponed with the use of technology. For all these reasons, most patients, families, and physicians are forced to make decisions about how, when, and where they will die.

The Right to Refuse Care and Advance Directives

Most patients fear death or dying, and want to have some control over the circumstances in which they die. If a severely ill patient has decision-making capacity—i.e., is mentally capable of making informed choices—she has a virtually absolute right to refuse any treatment, including life-sustaining treatment. This basic principle is at the root of any requirement for informed consent for medical treatment, and is most important when life and death are at issue. It is therefore obligatory for physicians to discuss anticipated treatments with competent patients. *Competence* is the legal term for someone with decision-making capacity.

There are no simple tests for determining when a patient has decision-making capacity. One important concept to remember is that a person can have the capacity to make some decisions but not others. Ultimately, the provider should attempt to determine if the patient can understand the decision that has to be made, and shows the ability to give reasons for making a particular choice. The fact that the patient has a particular type of psychiatric illness, for example, or that a court has found them incompetent to control their finances, should not necessarily exclude the patient from playing a role in the decision-making process.

Because many patients lack decisional capacity when decisions need to be made, they often express their wishes ahead of time through *advance directives*. An advance directive can be written, but spoken statements can be legally valid directives as well. Written directives include *living wills*—which specify conditions or treatments which the patient would or would not want—or a *durable power of attorney for health care*—which gives legal authority to someone close to the patient to make health care decisions. The Patient Self-Determination Act (PSDA), which was enacted in 1990, is a federal law which requires health care institutions to inform patients of their right to complete an advance directive. (See Handouts/Overheads 1 and 2 for a sample Living Will and a sample Durable Power of Attorney for Health Care. Participants should be encouraged to become familiar with the forms of these documents that are commonly used in their states. The Choice in Dying web site mentioned in the Resources section includes sample copies of such documents for all states.)

In spite of the increased attention being given to advance directives, most persons still have not completed one of these documents. It is, admittedly, difficult for a person to think about what they might want done when they are very ill or even dying. Accordingly, many states have enacted surrogacy laws that create a type of "priority list" of persons who can make decisions on behalf of an incompetent patient, even if they have

never completed any form of advance directive. Health care providers should become familiar with whether such a law exists in their state, and if so, what the law says.

In addition, providers should become familiar with the cultural background of their patients. Depending on a patient's culture or ethnic background, for example, a provider's suggestion about withdrawing care might be incorrectly perceived as an attempt to wrongfully deny care to which the patient is entitled. In certain cultures, and for patients with certain religious beliefs, withdrawing care might be viewed as immoral. The health care provider should explore the growing medical ethics literature about the diversity of patient backgrounds. This is particularly important when the provider's practice regularly involves contact with patients from a specific cultural group.

Physician Assisted Suicide

While it is both legal and ethical for a provider to assist a patient in dying by accepting their wish to forego care (sometimes called passive euthanasia), actively causing a patient's death (active euthanasia) is generally illegal. A health care provider may not legally kill a patient by injecting a lethal substance. In most states it is illegal for a provider, a relative, a friend—indeed, anyone—to assist a patient in killing himself. Simply put, assisted suicide is usually illegal. (Oregon is the only state that has a specific law authorizing assisted suicide. Handout/Overhead 3 describes that law.)

Those who believe that the distinction between active and passive euthanasia is morally important emphasize the role of the physician, pointing out that in passive euthanasia, the patient dies from a natural process. They believe it is important for physicians to be seen and trusted as healers, not as killers. Those who support physician assisted suicide and active euthanasia emphasize the right of patients to make autonomous choices, and believe it is consistent with medical traditions for physicians to help patients die in a comfortable, dignified manner of their own choosing. They also point out that many patients suffer from chronic diseases and want to die, but their disease will not kill them soon enough. They may want and need a physician's help to avoid years of unwanted and painful existence.

Areas of Controversy in End-of-Life Decision-Making

While there is general agreement that competent patients should be allowed to make their own decisions, difficulty and disagreements arise over several issues. First, there can be difficulty in determining whether a patient actually is competent to make decisions, particularly when illness or drugs cause his mental status to change from day to day or even hour to hour. Second, patients commonly change their mind, and it is difficult to know which choice is an authentic one, even when the patient is clearly competent: a request to discontinue treatment at one time, or an insistence that "everything be done" eight hours later. Finally, the decisions of surrogates are sometimes questioned, even if they have the legal authority to make decisions because of an advance directive appointing them as the patient's chosen decision-maker. These surrogates sometimes request decisions which, in the opinion of physicians or other family members, do not

appear to be in the patient's best interests, or do not appear consistent with what the patient would want.

In response to these and other problems, hospitals have created ethics committees to develop policies and to consult on difficult cases. The Joint Commission on the Accreditation of Healthcare Organizations requires accredited institutions to have an ethics committee or some other mechanism for assisting patients and health care providers in resolving ethical disputes.

SECTION 4 CASE STUDY/DISCUSSION QUESTIONS

Rachel Larson is 52–years–old, and has been living with multiple sclerosis for 19 years. She lives alone and is paraplegic, incontinent, wheelchair bound, and dependent on home visitors. She is in the hospital getting intravenous antibiotics for her pneumonia.

During the several months prior to this hospitalization, she has experienced difficulty swallowing, which you believe may be merely a temporary exacerbation of her multiple sclerosis symptoms. Nonetheless, you believe that her resulting weight loss is endangering her life, and you advise her of the need to temporarily place a nasogastric tube so that her calorie intake may be substantially increased.

You are quite surprised when she refuses the nasogastric tube. In fact, she tells you that she is tired of her current miserable life, and if her weight loss is truly endangering that life, then she would just as soon remain in the hospital until she dies of malnutrition.

1. Should you be willing to go along with this request?

2. After learning that it would take quite a few weeks to die of malnutrition, she also requests that you stop the intravenous fluids. How should you respond?

3. She also requests that you provide her with sedatives to make sure she does not suffer. What is your response? Should you worry about being an assistant to her suicide?

4. Would your answer to question 1 change if she had allowed the placement of a nasogastric tube a few days earlier, and was now demanding that you remove it?

5. Assume that you never had any discussions with Rachel, but that during the hospitalization she had lapsed into unconsciousness, and you were again about to use a nasogastric tube to improve her nutritional status. However, at that point her brother showed up with a valid durable power of attorney for health care, stating that he knew she would not have wanted the tube placed. How do you respond?

SECTION 5 SUGGESTED ANSWERS

1. *Should you be willing to go along with this request?*

   The simple answer is *yes*, but the important point is to understand why this answer is correct. There are two important issues to discuss.

   Unlike most cases in which patients may be refusing treatment, Rachel is not "terminally ill": it is quite possible that she might live for many more years, given adequate medical care. Thus, we must ask whether the right to refuse life-sustaining treatment extends to such people. It is well accepted that it does, at least where the patient is severely ill and is suffering. It is theoretically possible to come up with a case in which there might be doubt about a patient's authority to refuse case because they are not "suffering" enough. For example, one might think twice about allowing an 18-year-old diabetic boy to refuse his insulin injections, because he wanted to join his girl friend who recently was killed in an auto accident, even if he demonstrates that he is not clinically depressed. Nonetheless, such a case would be an uncommon exception to the rule that patients with significant medical problems almost always have to right to refuse life-sustaining medical treatment, even if it means that they will die as a result.

   The second issue worth discussing relates to what Rachel is refusing: food and fluids. For many years, there was extensive discussion about whether this constitutes medical care, even if it can only be administered "artificially", such as through a nasogastric tube. The well-recognized consensus is that under such circumstances, this is indeed medical care, and a patient has just as much a right to refuse artificially administered food as to refuse any other form of medical treatment. In either case, administering the treatment against the patient's will would be overriding their autonomy to control their body and to keep it free from unwanted invasions.

2. *After learning that it would take quite a few weeks to die of malnutrition, she also requests that you stop the intravenous fluids. How should you respond?*

   As suggested in the answer to question 1, there is currently no difference in how we treat requests to stop artificially administered food, artificially administered fluids, or any other form of medical treatment. You should comply with her request.

3. *She also requests that you provide her with sedatives to make sure she does not suffer. What is your response? Should you worry about being an assistant to her suicide?*

   This request might be viewed as raising a more difficult issue than the previous questions. In the prior requests, Rachel was merely refusing care, and exercising her right not to have her body violated. In this situation, she is asking for active intervention by you. In a sense, you might view it as if you would now be an

assistant to her in her desire to die. Perhaps you are worried that your actions in helping her might not only be unethical, but might also constitute assisted suicide.

In fact, giving her the sedatives would be neither unethical nor illegal. From an ethical viewpoint, you are merely fulfilling your duty to make your patient comfortable. Indeed, there are even cases where fulfilling that duty can actually hasten a person's death, such as when the dose of morphine necessary to relieve a patient's pain will also significantly depress their respiration. This is often considered acceptable under the doctrine of double effect. This principle states that an action which might otherwise be wrong (such as killing) can be permissible if it is an unintended, even though expected, consequence of an action that is morally acceptable (such as relieving pain).

As for the legal issues, you would have no risk of being involved in assisted suicide, since your patient is not committing suicide. She is merely asking for relief from suffering while she exercises her right to be free from unwanted medical care (the nasogastric tube and the intravenous lines). Her exercise of that right is not considered suicide. Anyone who has doubts about this might look at the well-known case of Elizabeth Bouvia (*Bouvia v. Superior Court*, 179 Cal. App. 3d 1127 (1986)). Ms. Bouvia's condition was similar to that of Rachel, and she was in a public hospital in California. Not only did the court order the hospital to comply with her refusal of a nasogastric tube, it also noted that the hospital "may not deny her relief from pain and suffering" merely because she chose to die in a public hospital. As it stated, it "certainly is not illegal or immoral to prefer a natural, albeit sooner, death than a drugged life attached to a mechanical device."

You should distinguish this situation from what happens with Jack Kevorkian's patients, as discussed in the Ice Breaker. His patients need his help because they do not have the ability to cause their death by merely refusing a specific kind of medical care. In effect, once your continued life depends on a particular kind of treatment, you now have the ability to legally die by merely refusing that treatment. (You might take a look at Handout/Overhead 3, which describes the Oregon Death With Dignity Act, to contrast which patients would come under that provision. Ask the participants if a terminally ill patient who also needs a ventilator, and who wants to die, really should care whether they are in Oregon as opposed to any other state.) Whether or not the dividing line between Kevorkian's patients, and patients such as Rachel or Elizabeth Bouvia, makes sense from an ethical or legal perspective is an interesting question.

By the way, none of these rules should be viewed as forcing a particular health care provider to participate in an action that they personally view as immoral. However, it would be the duty of that provider to remove themselves from the care of the patient, and make sure that an alternative provider is available who will respect the wishes of the patient.

Finally, it might be noted, as a clinical matter, that patients who choose to die by rejecting food and fluids usually do not suffer greatly. Thus, there may in fact not be a great need in such cases for large amounts of sedatives or pain killers.

4. *Would your answer to question 1 change if she had allowed the placement of a nasogastric tube a few days earlier, and was now demanding that you remove it?*

No, your answer should be the same: you should be willing to remove it. This question raises the possible difference between withholding a life-sustaining treatment (e.g., never starting it) and withdrawing that treatment after it has begun. While in the past it was sometimes argued that it was "less ethical" to withdraw a treatment after it had been started, it is now generally accepted that there is no legally or morally significant difference between withholding a treatment or withdrawing that treatment. Indeed, it often makes most sense to try a treatment, and then, after it has been conclusively demonstrated that it does not work, or that the patient is continuing to suffer, to stop the treatment. Withdrawing a treatment is, however, often more stressful for the providers, because it seems to involve an action, rather than inaction.

5. *Assume that you never had any discussions with Rachel, but that during the hospitalization she had lapsed into unconsciousness, and you were again about to use a nasogastric tube to improve her nutritional status. However, at that point her brother showed up with a valid durable power of attorney for health care, stating that she would not have wanted the tube placed. How do you respond?*

Ultimately, as an ethical matter, the question confronting you is no different than before: you have to determine what Rachel would have wanted. In this case, it is somewhat more difficult, since you only have her brother's view. An important part of your analysis should involve examining the advance directive to make sure that it covers the type of decision that is being contemplated. (Handouts/Overheads 1 and 2 provide samples of a living will and a durable power of attorney for health care.) In particular, as a legal matter, state laws often differ regarding how specific a directive must be with regard to terminating artificially administered food and fluids, and under what circumstances they can be withheld.

SECTION 6 SUGGESTED READING

1. Alpers A, Lo B. Physician-assisted suicide in Oregon: A bold experiment. *Journal of the American Medical Association* 1995;274:483–487.
   A balanced and thorough analysis of the many questions and complexities of Oregon's recent law allowing physician-assisted suicide.

2. Annas GJ. The health care proxy and the living will. *New England Journal of Medicine* 1991;324:1210–1213.
   An excellent discussion of the differences between various kinds of advance directives, with useful advice on how to discuss these documents with a patient.

3. Berger JT. Culture and ethnicity in clinical care. *Archives of Internal Medicine* 1998;158:2085–2090.
   A discussion of a variety of areas in which a patient's culture or ethnicity may affect medical decision-making, such as advance directives, treatment preferences, autopsy and organ donation, and truth-telling. Extensive references are provided.

4. Chin AE, Hedberg K, Higginson GK, Fleming DW. Legalized physician-assisted suicide in Oregon: The first year's experience. *New England Journal of Medicine* 1999;340:577–583.
   A very interesting and information-filled report discussing what actually has happened in Oregon after the passage of the law allowing physician-assisted suicide.

5. Hall MA, Ellman IM, Strouse DS. *Health Care Law and Ethics.* Chapter 7, The Law and Ethics of Withholding Medical Care and Assisting Suicide. St. Paul, Minn.: 2nd ed., 1999.
   A well-written and comprehensive discussion of the current legal and ethical thinking about the right to refuse medical care.

6. Menikoff JA, Sachs GA, Siegler M. Beyond advance directives: Health care surrogate laws. *New England Journal of Medicine* 1992;327:1165–1169.
   A discussion of state laws which automatically appoint family members and others to act as surrogates for someone who has not completed any advance directive.

7. Murphy ST, Palmer JM, Azen S, Frank G, Michel V, Blackhall LJ. Ethnicity and advance directives. *Journal of Law, Medicine and Ethics* 1994;24:108–117.
   An interesting study raising many questions about how a patient's ethnic background may influence the use of advance directives.

SECTION 7 RESOURCES

1. Leo Media, Inc.
   Distributor of a series of videotapes on legal and ethical issues in health care. Among those that are of some relevance to this topic are:

   Born Dying. Examines ethical issues in deciding whether to treat or not to treat a multiply handicapped baby.

   Better Off Dead. Originally aired on the *Frontline* television series, this video also discusses issues relating to appropriate care for severely handicapped babies.

   The DNR Dilemma (2 parts). Dramatizes a physician's anxiety about how to discuss do-not-resuscitate orders with a dying patient.

   Living Choices. A "lay audience" discussion about the importance of completing advance directives.

   No Heroic Measures. Discussion of the legal and ethical issues involved in removing a feeding tube from a demented, elderly patient.

   Contact: Leo Media, Inc. www.leomed.com/catalog/legal.htm, or call (217) 337-0700.

2. Choice in Dying. www.choices.org
   Collection of advance directives for every state in the U.S., with accompanying directions. In addition, Choice in Dying has a videotape collection, among which are:

   Dax's Case. Discussion of one of the most famous cases about refusing care, that of Dax Cowart, who was horribly burned in a gas explosion, and was treated for his burns even though he begged to be allowed to die. He ultimately went on to recover (and become a lawyer) in spite of incredible handicaps, yet has continually maintained that he should have originally been allowed to die.

   Whose Death Is It, Anyway? A PBS documentary hosted by ABC-TV's Dr. Nancy Sniderman, involving five families discussing decisions relating to death and dying.

3. MedEthEx. MCP Hahnemann University. griffin.auhs.edu/dept/medethic
   Multi-media series of four ethics cases on the web. Case 2 involves a man with cancer asking for a prescription for a large number of sleeping pills. An extensive bibliography is provided.

4. Ethics in Medicine. University of Washington School of Medicine. eduserv.hscer.washington.edu/bioethics/topics/eol.html
Two brief cases involving end-of-life issues, with accompanying discussion and a bibliography.

5. Consent and Capacity. University of Toronto Joint Centre for Bioethics. www.utoronto.ca/jcb/end_of_life.htm
Extensive collection of links relating to end-of-life ethical issues. Included are links to (1) the Royal College of Physicians and Surgeons of Canada Bioethics Education Project, which has on-line cases involving end-of-life issues for a number of different medical disciplines (medicine, obstetrics and gynecology, psychiatry and surgery), and (2) the 14-part series of articles entitled "Bioethics for Clinicians", which was published in the Canadian Medical Association Journal, and is available on-line (including Part 5, Substitute Decision Making, and Part 11, Euthanasia and Assisted Suicide).

6. Oregon's Death With Dignity Act. Oregon Health Division. www.ohd.hr.state.or.us/cdpe/chs/pas/pas.htm
The official web page for the division of the Oregon state government that is in charge of administering the law that permits physician-assisted suicide. It includes the full text of the report describing the results of the first year after enactment.

7. The Ethical Question. American Medical Association, 1993.
One of the four videotapes (with accompanying study guides) in this package is entitled "Death and Dying," and covers various ethical issues relating to the care of dying patients. Another of the videotapes is entitled "Physician-Assisted Suicide," and discusses the differences between physician-assisted suicide, withdrawing care, and euthanasia, and also deals with the ethical appropriateness of these various practices.

Contact: Write to the AMA at Division of Continuing Medical Education, American Medical Association, 515 North State Street, Chicago, IL 60610, or call 800-621-8335.

8. Fanlight Productions. www.fanlight.com
This company offers for sale an extensive collection of videotapes on health care issues. Among those relevant to this topic are:

> *The SUPPORT Project: To Improve Care at the End of Life*. An introduction to a major and controversial national study about end-of-life decision-making.
>
> *The Right to Decide*. Designed to educate health care professionals about how to discuss advance directives with patients.

To Choose No Harm: Ethical Decision-Making at the End of Life. Resolving conflicts between the wishes of patients and the judgments of health care providers.

Help Me Die. How to deal with patients' requests for assistance in ending their lives.

Dreams & Dilemmas. Discusses the unique issues relating to health care decisions concerning infants in a neonatal intensive care unit.

A Fate Worse Than Death. Making decisions about withdrawing care from a patient in a coma or persistent vegetative state.

The Way We Die. How health care professionals should work with patients to develop end-of-life care plans.

Contact: In addition to using the web site address given above, you can write to Fanlight Productions, 47 Halifax Street, Boston, MA 02130, or call 800-937-4113.

SECTION 8 HANDOUTS/OVERHEADS

(Attached)

A Sample Living Will (Illinois)

This declaration is made this ..... day of ..... (month, year).

I, ..., being of sound mind, willfully and voluntarily make known my desires that my moment of death shall not be artificially postponed.

If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition by my attending physician who has personally examined me and has determined that my death is imminent except for death delaying procedures, I direct that such procedures which would only prolong the dying process be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.

In the absence of my ability to give directions regarding the use of such death delaying procedures, it is my intention that this declaration shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

Signed.....

City, County and State of Residence.....

The declarant is personally known to me and I believe him or her to be of sound mind. I saw the declarant sign the declaration in my presence (or the declarant acknowledged in my presence that he or she had signed the declaration) and I signed the declaration as a witness in the presence of the declarant. I did not sign the declarant's signature above for or at the direction of the declarant. At the date of this instrument, I am not entitled to any portion of the estate of the declarant according to the laws of intestate succession or, to the best of my knowledge and belief, under any will of declarant or other instrument taking effect at declarant's death, or directly financially responsible for declarant's medical care.

Witness.....

Witness.....

HANDOUT/OVERHEAD 1

A Sample Durable Power of Attorney for Health Care (Kansas)

I, _____, designate and appoint _____ (name, address and telephone number) to be my agent for health care decisions and pursuant to the language stated below, on my behalf to:

(1) Consent, refuse consent, or withdraw consent to any care, treatment, service or procedure to maintain, diagnose or treat a physical or mental condition, and to make decisions about organ donation, autopsy and disposition of the body;

(2) make all necessary arrangements at any hospital, psychiatric hospital or psychiatric treatment facility, hospice, nursing home or similar institution; to employ or discharge health care personnel to include physicians, psychiatrists, psychologists, dentists, nurses, therapists or any other person who is licensed, certified or otherwise authorized or permitted by the laws of this state to administer health care as the agent shall deem necessary for my physical, mental and emotional well being; and

(3) request, receive and review any information, verbal or written, regarding my personal affairs or physical or mental health including medical and hospital records and to execute any releases of other documents that may be required in order to obtain such information.

In exercising the grant of authority set forth above my agent for health care decisions shall: _____ (Here may be inserted any special instructions or statement of the principal's desires to be followed by the agent in exercising the authority granted).

LIMITATIONS OF AUTHORITY

(1) The powers of the agent herein shall be limited to the extent set out in writing in this durable power of attorney for health care decisions, and shall not include the power to revoke or invalidate any previously existing declaration made in accordance with the natural death act.

(2) The agent shall be prohibited from authorizing consent for the following items: _____

(3) This durable power of attorney for health care decisions shall be subject to the additional following limitations: _____

EFFECTIVE TIME

This power of attorney for health care decisions shall become effective upon the occurrence of my disability or incapacity.

REVOCATION

Any durable power of attorney for health care decisions I have previously made is hereby revoked.

EXECUTION

Executed this _____, (date) at _____, (county) Kansas.

_____ (principal)

This document must be: (1) Witnessed by two individuals of lawful age who are not the agent, not related to the principal by blood, marriage or adoption, not entitled to any portion of principal's estate and not financially responsible for principal's health care; OR (2) acknowledged by a notary public.

(Signature lines and notary provisions, which would normally follow, are not provided in this sample.)

HANDOUT/OVERHEAD 2

Oregon Death With Dignity Act

The Oregon Death With Dignity Act, passed in 1995, is the first state law in the United States that specifically allows "physician-assisted suicide."

In particular, an adult resident of Oregon who has an incurable and irreversibly disease that is likely to lead to death within the next six months can ask a physician to write a prescription for a lethal dose of medicine. There are various procedural requirements to make sure that this is what the patient really wants, and that they are competent and are acting without any compulsion.

Here is the written request that a patient is required to sign:

REQUEST FOR MEDICATION TO END MY LIFE IN A HUMANE AND DIGNIFIED MANNER

I, ----------, am an adult of sound mind.

I am suffering from ----------, which my attending physician has determined is a terminal disease and which has been medically confirmed by a consulting physician.

I have been fully informed of my diagnosis, prognosis, the nature of medication to be prescribed and potential associated risks, the expected result, and the feasible alternatives, including comfort care, hospice care and pain control.

I request that my attending physician prescribe medication that will end my life in a humane and dignified manner.

INITIAL ONE:

---------- I have informed my family of my decision and taken their opinions into consideration.

---------- I have decided not to inform my family of my decision.

---------- I have no family to inform of my decision.

I understand that I have the right to rescind this request at any time.

I understand the full import of this request and I expect to die when I take

the medication to be prescribed.

I make this request voluntarily and without reservation, and I accept full moral responsibility for my actions.

Signed: ----------

Dated: ----------

DECLARATION OF WITNESSES

We declare that the person signing this request:

(a) Is personally known to us or has provided proof of identity;

(b) Signed this request in our presence;

(c) Appears to be of sound mind and not under duress, fraud or undue influence;

(d) Is not a patient for whom either of us is attending physician.

---------- Witness 1/Date

---------- Witness 2/Date

NOTE: One witness shall not be a relative (by blood, marriage or adoption) of the person signing this request, shall not be entitled to any portion of the person's estate upon death and shall not own, operate or be employed at a health care facility where the person is a patient or resident. If the patient is an inpatient at a health care facility, one of the witnesses shall be an individual designated by the facility.

HANDOUT/OVERHEAD 3

SUBTOPIC 4

ETHICAL ISSUES IN MANAGED CARE

TIMELINE (60 minutes)

5 min	Introduction/Ice Breaker
5 min	Review of Objectives
10 min	Overview
35 min	Review of Case/Questions
5 min	Additional Questions and Answers

SECTION 1 LEARNING OBJECTIVES

Target Group: Physicians in training and in practice, nurse practitioners/trainees, physician assistants/trainees, and other health professionals/trainees.

By the end of this discussion, participants should be able to:

1. Understand the concept of a fiduciary relationship.

2. Understand how different methods of compensating providers can create conflicts of interest between them and their patients.

3. Be able to describe why it may be ethical, in a managed care environment, for a provider to make choices that benefit some patients and hurt others.

4. Discuss disclosure to patients of information relating to medical care withheld for cost-saving reasons.

SECTION 2 ICE BREAKER

The facilitator should ask each participant to think about (and write down) ways in which their financial interests have conflicted with those of their patients, either in their current job or in previous jobs. These responses should then be read aloud, and an effort should be made to put them into categories according to the types of conflicts. Participants should be encouraged to discuss specific dollar amounts. How should you determine whether a specific amount is enough of a conflict to worry about?

SECTION 3 OVERVIEW

The manner in which medical care is delivered to patients is obviously changing rapidly. While politicians debate what form of health care reform should be implemented, the private health care sector has been responding to demands by employers to provide lower-cost care. Where only a few decades ago a physician working as a sole practitioner was the predominant form of care, now that is a relative rarity. Most doctors now work together in group practices, or work directly for some form of managed care organization, such as a health maintenance organization (HMO). Moreover, doctors have been joined by a wide array of other health care practitioners who also are providing primary care, such as nurse practitioners and physician assistants.

The new world of medical care has created new ethical dilemmas. It is important that every health care provider have an understanding of the underlying ethical principles by which they can navigate these new uncharted waters. Most importantly, they should be able to distinguish (a) situations in which their own interests may conflict with those of a patient, from (b) situations in which they will have to resolve conflicts between the interests of different patients.

Patient versus Provider Conflicts

A health care provider has a fiduciary relationship to her patients. The term fiduciary comes from the law, where it originated when people gave their money to someone (a trustee) who would invest it on their behalf. The trustee was held to be obligated to look out for the best interests of the owner of the money. She could not be herself in a position in which her best interests would conflict with those of the owner. Thus, for example, it would be inappropriate for the trustee to invest the money in her own business, since her determination about the appropriateness of such an investment was likely to be biased by the benefits to herself.

In a similar manner, a health care provider must also look out for the patient's best interests and avoid being in a position where her own interests conflict with those of the patient. This is easier said than done. In the traditional world of fee-for-service, there was a very direct conflict: health care providers got paid by doing more, as opposed to preventing illness. Thus, there was a direct incentive *not* to cure the patient. Indeed, there are studies strongly suggesting that the overuse of certain medical procedures has been linked to just such financial incentives.

The new organizations for providing medical care have also led to new compensatory mechanisms. These, in turn, create new possibilities for conflicts between the interests of health care providers and patients. Perhaps the most conflict-free way to compensate a health care provider is to have them work on salary. In this manner, there is no direct connection between the manner in which the patient is treated, and the amount of money that goes to the provider.

For better or for worse, a salaried provider has no direct incentive to try to save money for their employer. Accordingly, many providers of health care, such as managed care

organizations, have created compensation packages that directly link the provider's compensation to the amount of resources that they expend on patient care. For example, a physician assistant may be entitled to a bonus whose size depends on how low the cost of the tests they ordered during a particular year is. The fewer tests they order, the more that their bonus is. Notice how we have flipped the incentives that existed in the fee-for-service world: where we previously were worried that the provider had an incentive to provide too many tests and procedures, we are now concerned that there is an incentive to provide too few tests and procedures.

Similar issues can exist even outside of managed care organizations. Assume, for example, that a group of physicians receives a large portion of its income by contracting with insurance companies to provide for care of patients under a capitated arrangement. In other words, for those patients, the group is agreeing to provide all the care that they need during the year, and in return the group receives a fixed dollar amount per patient. In effect, all the care that is given to the patients comes directly out of the pockets of the doctors. Some might consider that to create a possible incentive to minimize the cost of the care that is given to the patients. Others would argue that such behavior would be short-sighted, since by giving the patients appropriate care, the providers will ultimately minimize the costs of keeping the patients healthy. Adding to the confusion is the fact that these arguments depend on various assumptions with regard to how long patients on average remain with a particular provider. Given the continuing changes in the health care field, that is a particularly difficult thing to predict.

In all of the situations in which financial incentives of providers might be viewed as conflicting with the best interests of patients, there is active debate about how best to resolve these conflicts. Perhaps the most widely accepted conclusion is that all of these new arrangements do create conflicts to some degree or another, and it is necessary to evaluate the compensation arrangements to make sure that the economic incentives to the provider are not so huge as to unreasonably influence provider behavior. Such would likely be the case, for example, if a very large percentage of the provider's income—say, 50%—was tied to a bonus that related to the number of tests ordered.

Conflicts between Interests of Patients

There is a very different kind of conflict that can occur in the new world of cost constraints. It has traditionally been said—consistent with the notion that health care providers are fiduciaries—that they must keep the interests of the patient in the forefront at all times. This is a principle that was commonly accepted, in particular, by physicians in prior decades, when most practiced as sole practitioners.

There is a growing recognition that this principle may not apply with equal vigor in the world of managed care. In particular, many health care providers now work for organizations that serve a large group of patients and whose ability to continue to serve those patients effectively depends on controlling costs. Each dollar that is spent on one patient is a dollar that is not available to spend on a different patient. Given that a particular organization only has a finite amount of money, difficult decisions will likely have to be made with regard to rationing care. Since health care providers are the ultimate

decision-makers in terms of deciding many aspects of what elements of care a particular patient will get, they will also be playing a role in making some of these rationing decisions. How they should make these decisions is a question that is only now beginning to be explored. The case that follows tries to address this within a specific setting, so as to give the provider a concrete example of how it might sometimes be appropriate to deny a particular patient "useful" care solely for cost-saving reasons.

Providers should of course always be careful to avoid letting health care decisions be influenced by irrelevant and improper criteria, such as a patient's sex, race, or ethnicity (at least, in cases where those factors do not directly influence the patient's actual medical condition). There is evidence that such irrelevant factors are already leading to a discriminatory distribution of health care resources. It would be particularly troublesome if attempts to control health care costs ended up having a further disproportionate impact on those members of our society who are already being denied their fair share of health care.

SECTION 4 CASE STUDY/DISCUSSION QUESTIONS

You are working for an HMO that serves a high poverty, inner-city community. Your employer has contracted with the state Medicaid agency to accept a fixed dollar amount for each of the patients it serves and in return to meet the basic health care needs of these patients.

Brandy Smith is a 25–year–old asthmatic patient whom you have been taking care of for about a year. You know that she is on welfare and has a son and daughter, ages 2 and 5. She is a good single parent—the children's father died in an accident shortly after the younger child was born—and she works hard to make ends meet.

During her clinic visit this week, she mentions that on TV, she had seen a commercial about a new asthma medication, and she was wondering if it might be better than what she is on. You know that her current medication costs about $2 a week, while the new medicine costs about $20 a week. All her medication costs are covered by the HMO, however, so the actual cost difference would be irrelevant to her.

The new medication primarily differs from her current one is that it produces a slightly lower incidence of side effects (occasional nausea). It is not on the HMO's formulary, although you know that by filling out a lot of paper work, you could probably get it approved for use by Ms. Smith.

1. Should you try to have the drug approved for use by Ms. Smith?

2. Should it matter if Ms. Smith is having a lot of problems with nausea? Why or why not?

3. Suppose that Ms. Smith came in for her usual appointment, and never mentioned the new drug. Should you mention it to her?

4. Assume that the new drug was not only not on the formulary, but that there was no way that you could provide it under the HMO rules. If Ms. Smith asked whether there were any better drugs that she could be using, what would you say? What if the HMO rules prevented disclosing this information?

SECTION 5 SUGGESTED ANSWERS

1. *Should you try to have the drug approved for use by Ms. Smith?*

This question directly confronts the issue of when—if ever—you, as a provider, can do something that is to some extent "inconsistent with" doing all that you can to improve the health of your patient. Clearly, the new drug will have fewer side effects, and so your patient's health will be improved (albeit only slightly) if she gets this drug. Moreover, it would not cost her anything extra. To the extent that prescribing the drug to her causes extra costs for the HMO, her share of those costs is essentially zero (assuming they are in essence spread out among the thousands of patients who belong to the HMO). These arguments would seem to suggest that it is appropriate for you to get her the drug.

There are, however, substantial arguments supporting the proposition that it is perfectly ethical to not give her the new drug. Those arguments are most compelling under the assumption that Ms. Smith's incidence of side effects under the old drug is "average": she is only occasionally suffering from nausea, and it is not an especially bad problem for her. Under those circumstances, it is likely that, if she had to pay for the new drug out of her own funds, she would not pay $20. Let us assume she would only pay $5, for example.

To simplify things, let us imagine that there is only one other patient in the HMO, and that patient's medical condition is identical to Ms. Smith's. In other words, there would be a similar decision about whether or not that other patient gets the new drug. If we follow the "traditional" analysis of having the provider do everything they can to benefit the patient in front of them, we will end up providing the new drug to both patients. The result, however, will be that $40 of the HMO's budget ($20 for each of the two patients) will be spent on medications that only provide benefits of $10 ($5 for each of them). In effect, $30 has been wasted.

On the other hand, let us assume that, as part of the agreement under which the patients had joined the HMO, each patient had agreed that the HMO, and its employees, would try to control costs in various circumstances, and thus benefit all the patients by assuring that funds would be available for important health care expenditures. Under this mandate, the provider could deny the expensive drug to both Ms. Smith and the other patient. In this instance, they would both get the $2 drug, which we will assume really was worth $2 to each of them. By imposing this restriction on the activity of the provider, we save the $30 that was "waste" in the other scenario. In effect, by consenting to a rule that restricts the ability of the provider to give out expensive drugs, both patients are made better off.

2. *Should it matter if Ms. Smith is having a lot of problems with nausea? Why or why not?*

The instinctive response—that it should matter—is correct. As for why, note that if Ms. Smith is having a great deal of difficulty with nausea, then she would probably be willing to pay more money for the new drug—or, equivalently, there is less "waste" in giving her that drug, since its value to her is much closer to its cost. (For example, she might in fact be willing to pay $20 for that drug, and there would be no "waste" at all.)

In other words, even if a particular medication or treatment has been rejected on "cost-benefit" grounds for a general class of patients, there may be a specific reason why it is particularly useful for a particular patient. It is perfectly appropriate for the provider to recognize this fact and then prescribe the drug for that patient. At the same time, however, you should recognize that in the *absence* of such a determination, there should be an assumption that the general conclusion will apply to the "non-unique" patient: the added benefits of the drug do not justify the added costs, and it should not be prescribed even though it is better.

3. *Suppose that Ms. Smith came in for her usual appointment, and never mentioned the new drug. Should you mention it to her?*

To answer this question, we must first determine what the possible benefit is to Ms. Smith from having this information. Under the analysis in the answer to the previous question, we might have concluded that it is ethical for the provider to determine that Ms. Smith is not entitled to get the drug under the HMO rules. Nonetheless, it is possible that Ms. Smith's values differ from those of the "average" HMO patient. Maybe even a little bit of nausea is very troubling to her, and it would in fact be worth $25 to her to have less nausea. Under these circumstances, she should be willing to pay for the drug out of her own money, even if it is not provided under the HMO rules. But if the provider doesn't tell her about the drug, she cannot make this decision.

This line of thinking, if extended, might suggest that the provider would have to tell every patient about every new drug, even if they are not being paid for under the HMO formulary. Some commentators have suggested that this is an unreasonable burden. Furthermore, they would justify withholding such information on the same theory by which patients are deemed to have consented to allowing their providers to save costs by withholding certain medications and treatments. In other words, the contract through which the patient joined the HMO would both warn the patient that cost savings would occur, and that the patient would not be told when decisions based on cost savings are taking place. (Indeed, some would argue that such decisions are almost always taking place.)

It remains to be seen how the limits of the ethical duty to tell patients about "withheld" treatments will develop. It is likely that, even if there are warnings in

the contract signed by the patient that the HMO need not disclose cost-savings measures when they are actually affecting a patient's care, the provider will nonetheless still be required to tell the patient in certain types of specific situations. At present, the best that can be said is that some such situations seem obvious. For example, if a patient is dying of liver failure, and yet the HMO does not cover the costs of a transplant, it would seem highly unethical to not mention to the patient that a liver transplant could cure them.

4. *Assume that the new drug was not only not on the formulary, but that there was no way that you could provide it under the HMO rules. If Ms. Smith asked whether there were any better drugs that she could be using, what would you say? What if the HMO rules prevented disclosing this information?*

   This question raises an important issue in current discussions about managed care: to what extent can HMOs not only require that information be withheld from patients if not specifically requested, but actually require providers to lie to patients (or, at the least, say that they are not authorized to answer the question)? HMOs do at times have rules that specifically restrict providers from telling patients about certain expensive treatment options. The theory behind these rules, known as "gag rules", is that if patients learn about these excluded treatments, they will either think badly of the HMO, or perhaps more significantly, might take action to make sure they get the expensive treatment and that it is paid for by the HMO.

   Legislation is currently being debated by Congress (as of 1999) that may make such contract provisions illegal. (See Handout/Overhead 1 for a list of proposed provisions of such a law. It would be interesting to see how participants feel about each of these provisions, or, more generally, whether this is something that Congress should get involved with.) Even in the absence of such legislation, a provider should rarely refuse to answer a patient's specific request for relevant information relating to their treatment.

SECTION 6 SUGGESTED READING

1. Asch DA, Ubel PA. Rationing by any other name. *New England Journal of Medicine* 1997;336:16668–16671.
   An interesting presentation of specific cases designed to help determine what does or does not constitute rationing based on cost decisions.

2. Buchanan A. Managed care: Rationing without justice, but not unjustly. *Journal of Health Policy, Politics and Law* 1998;23:617–634.
   A defense of managed care, including attention to the criticism that managed care forces physicians to breach their fiduciary obligations to patients.

3. Emanuel EJ, Dubler NN. Preserving the physician-patient relationship in the era of managed care. *Journal of the American Medical Association* 1995;273:323–329.
   An informative overview of the ethical issues raised by the growth of manage care.

4. Gold M. Financial incentives: Current realities and challenges for physicians. *Journal of General Internal Medicine* 1999;14(Supp. 1):S6–S12.
   A survey of types of financial incentives currently being used in managed care.

5. Hall MA, Berenson RA. Ethical practice in managed care: A dose of realism. *Annals of Internal Medicine* 1998;128:395–-402.
   A discussion about the limits of ethical practice in a managed care environment by two authors who welcome many of the changes brought by managed care.

6. Kravitz RL. Ethnic differences in use of cardiovascular procedures: New insights and new challenges. *Annals of Internal Medicine* 1999;130:231–233.
   This editorial, and the articles it accompanies, can introduce the reader to the complex and conflicting literature about the extent of discrimination against patients on ethnic and related grounds.

7. Menikoff J. The role of the physician in cost control. *Ophthalmology Clinics of North America* 1997;10(2):191–195.
   A discussion of the legal and ethical issues relating to physicians' attempts to explicitly include cost control as an element in clinical decision-making.

8. Pearson SD, Sabin JE, Emanuel EJ. Ethical guidelines for physician compensation based on capitation. *New England Journal of Medicine* 1998;339:689–693.
   An interesting proposal for determining how one should decide whether a particular type of capitation arrangement is unethical.

9. Schulman KA, et al. The effect of race and sex on physicians' recommendations for cardiac catheterization. *New England Journal of Medicine* 1999;340:618–626.

In this fascinating study, 720 primary care physicians attending national meetings were shown interviews with hypothetical patients, and asked to make treatment recommendations. The results demonstrated that a patient's race and sex each independently influenced how the physicians would treat chest pain.

10. Ubel PA, Arnold RM. The unbearable rightness of bedside rationing: Physician duties in a climate of cost control. *Archives of Internal Medicine* 1995;155:1837–1842.
An argument for why physicians are ethically required to make cost-based decisions in the current health care environment.

SECTION 7 RESOURCES

1. Ethics in Medicine. University of Washington School of Medicine.
   eduserv.hscer.washington.edu/bioethics/topics/manag.html
   A brief case involving managed care issues, with a bibliography.

2. Consent and Capacity. University of Toronto Joint Centre for Bioethics.
   www.utoronto.ca/jcb/organizational_ethics.htm
   Extensive collection of links relating to organizational ethics. Included are links to (1) the Royal College of Physicians and Surgeons of Canada Bioethics Education Project, which has on-line cases involving resource allocation for a number of different medical disciplines (medicine, obstetrics and gynecology, psychiatry and surgery), and (2) the 14-part series of articles entitled "Bioethics for Clinicians", which was published in the Canadian Medical Association Journal, and is available on-line (including Part 13, Resource Allocation, and Part 17, on Conflicts of Interest).

3. The Ethical Question. American Medical Association, 1993.
   One of the four videotapes (with accompanying study guides) in this package is entitled "Economics and Health Care," and discusses issues such as the differences between a health care provider's duty to care for her patient, and society's duty to provide for a fair allocation of health care resources.

   Contact: Write to the AMA at Division of Continuing Medical Education, American Medical Association, 515 North State Street, Chicago, IL 60610, or call 800-621-8335.

SECTION 8 HANDOUTS/OVERHEADS

(Attached)

A Patient's Bill of Rights

The United States Congress is currently debating legislation to create a so-called "Patient's Bill of Rights" in order to help people deal with managed care organizations and insurance companies. Among the provisions that are being considered:

• Requiring plans to pay for emergency care in all situations that a "prudent lay person" would view as an emergency

• Requiring plans to pay for a patient's cost of participating in certain types of federally sponsored research trials.

• Requiring plans to disclose, when a person joins the plan, all financial incentives affecting each plan's health care providers.

• Preventing plans from restricting what a health care provider can tell a patient about available treatment options. As one proposed bill states, the employment contracts between employers and health care providers "shall not prohibit or restrict the provider from engaging in medical communication with the provider's patient."

• Requiring plans to provide greater opportunities to patients to challenge decisions denying specific types of care.

• Allowing patients to directly sue the managed care plans, as opposed to just the health care provider.

HANDOUT/OVERHEAD 1